

## HOW ARE DECISIONS MADE

### FINAL CODE BOOK

#### PRONOUNS:

1. Pronouns only are coded if they unambiguously refer to a certain subject which is codeable.
2. Pronouns referring to advance directives should be coded with the appropriate B code. The meaning of the entire statement said by the speaker, taken in context, determines which B code to use.
3. Pronouns referring to treatments or scenarios should only be coded if it is clear what treatment or scenario is the antecedent. (This may include C1 type scenarios, but only if the conversation has been about C1-type scenarios, and there is no question that that is what the pronoun refers to.)
4. Pronouns should generally **not** be coded as vague terms (even if the antecedent is a vague term). The only exception would be if the phrase containing the pronoun creates a **new**, previously uncoded, vague phrase.
5. Pronouns may be coded with an H code, if an H code clearly fits the turn.

#### SHORT PHRASES WITHOUT PRONOUNS

1. If the phrase is short and has no pronouns and does not **explicitly** refer to a codeable phrase or word, it should **not** be coded, even if the reference is clear, except as described below.
2. A brief phrase should be coded if it indicates one of the following (usually in answer to a preceding question or statement):
  - a. Presence of a living will (B2)
  - b. Affirmation of some fact or myth about advance directives (B6,B7).
  - c. Denial of the truth of some statement about advance directives (B6,B7).
  - d. A preference (D1, D2, or occasionally D3,D4)
  - e. Some fact about a medical procedure (E1)
  - f. That a proposed reason is or is not the reason for preferences (G2).
  - g. The presence or absence of a surrogate (H1)
  - h. Physician opinion of pt's preference (J7)

## Warnings

This section summarizes some easy to forget rules.

### MUTUALLY EXCLUSIVE CODES

Never code B1 in a turn where any other B code is coded.

Never code H1 in a turn where any other H code is coded.

### CODES THAT ALWAYS GO TOGETHER

F1d (Vegetable) and F1e (Terminally Ill) nearly always are coded with C1.

### CODES LIMITED TO PARTICULAR SPEAKERS

**Only Applies to MDs** (These codes are **never** used for other speakers.)

All **A** codes.

All **B4** codes (**B4a, B4b, B4c**)

**E3**

**G1**

**J5, J7, J8**

**Never Applies to MDs** (These codes are only used for pts and 3rd parties.)

All **D** codes.

**E2**

### FOR CODES WITH SUBCATEGORIES, YOU ALWAYS MUST CHOOSE A SUBCATEGORY.

Ex: You never just code **B4**; it must be **B4a** or **B4b** or **B4c**.

## A. FRAMING OF PURPOSE

- \* These codes refer to attempts made by a doctor to describe the purpose of these conversations in general or the purpose of this particular conversation. Either they describe why the doctor is bringing this up now or they describe what the general purpose of this enterprise is.
- \* These codes may be used regarding a reason for **completing** a living will.
- \* These codes should **not** be used if the statement refers to a reason for bringing a living will in (for which there may be no code).
- \* These codes may be used at **any** time in the conversation.
- \* If advance directives are explicitly mentioned in the turn (or referred to by pronoun), the proper B code should be used as well.
- \* These codes should only be used for the physician.

### A1. The discussion is for a research project.

- \* Any reference to the research project or taping that implies that at least part of the reason for the discussion is the research project.
- \* Statements which imply a link between the end of the advance directive discussion and turning off the tape recorder should be coded A1.
- \* Answers to patient-initiated concerns about taping procedures should not be coded A1 if it has not elsewhere been stated that one of the reasons for the discussion is the research project.
- \* Remember that patient-turns are never coded with A codes.

### A2. MDs are supposed to talk about this with their patients.

- \* Any statement that MD's "should" talk about this to their patients, or that others believe that MD's should talk about this to their patients. The implication of this is that there is **external** pressure on doctors to talk about this.
- \* "I'm bringing this up because it's something we should talk about."
- \* "They want us to talk about this."
- \* "The PSDA says we should talk about this."
- \* "Doctors are talking about this more and more."

### A3. Right to make decisions about one's own care.

- \* Code this when advance directives are explicitly linked to the fact that communicative pts have the right to authorize or refuse treatment.

### A4. To Determine what the Pt Would Want/Prevent Care Pt Would Not Want

- \* If (s)he cannot speak for himself/herself in the future.
- \* If A3 has been coded in a turn, A4 should **not** be.
- \* It is not necessary that the MD explicitly states that this is the reason for the discussion or for advance directives. It is sufficient that the MD state that (s)he wants to find out what the patient would want (using, more or less, those words).
- \* Statements that the purpose of advance directives is to determine what "you would want done" are included under this code.
- \* Statements that "I want to know what you would want," "I need to find out what you would want," etc. are included under this code.
- \* Statements that MD is trying to avoid situation which patient would not want are coded A4, as well.

### A5. MD generally talks to patients about this.

- \* Implies a general endorsement of the enterprise.
- \* "I generally talk to all my pts about this."

- \* "I try to talk to all my pts about this who are older than 65."

**A6. Prior Experience with Patient's Illness**

- \* Use this code only if the pt's prior illness is connected with the rationale for discussing this now.
- \* This code applies if there has been some illness in the past which makes the issue timely now, or if some chronic medical condition makes it worthwhile to discuss advance directives now.
- \* Medical illnesses which are not related to the timing of the discussion should not be coded A6.

**A7. Prior Experience with Illness in Family/Friend**

- \* Use this code only if the family member's illness is used to introduce the topic.

## **B. LIVING WILLS, ADVANCE DIRECTIVES, AND DPAS**

- \* These codes are meant to discuss the existence of these legal documents, how one might obtain one, and information regarding them. Turns about proxies who are not given formal DPA are not coded here.
- \* We will not distinguish between the type of legal document in these codes. Similar statements about LWs and DPAs will be coded similarly.
- \* Any turn in which DPA is mentioned by name should **also** be coded with the appropriate H code. However, pronouns referring to DPAs, when the discussion is primarily about the documentation aspect of DPAs (as opposed to the proxy aspect) should **not** be coded with an H code.
- \* Pronouns referring to DPAs or LWs should be coded with a B code. To determine which code should be used -- consider the context of the discussion and not only the turn being coded.

Example: Case 203

- 64. D: Wow. Well, what I'd like for you to do -- next time you come to see me -- can you bring that living will?
- 65. P: If I can find it. My wife will have to go... she, she'll take papers on top of papers and put a rubber band around them, stash 'em somewhere. I thought I had it in a little safe, but I, I don't it's there. It might be. (Code B3)
- 66. D: OK. Well... (No code)
- 67. P: I'll try to find it. (Code B3, even though pt doesn't explicitly say he will bring it in, clearly that is what he means.)

### **B1. Advance Directives -- NOS**

- \* Any time any form of formal advance directive is referred to (living will, DPA), when one of the codes below is not appropriate. This code should only be used in a turn where **no** other 'B' code is used.

### **B2. Existence of an Advance Directive**

- \* This should be coded for statements which are intended to establish the existence of an advance directive.
- \* Questions about where the living will is, what its contents are, etc. should **not** be coded here.
- \* Code this if the MD asks if there is a living will or DPA or if the pt states that there is one. (If the pt just answers 'yes' to a question about having a living will, it should be coded B2.)
- \* Do not code this for the pt or MD if the pt states that (s)he **does not** have a formal advance directive.

### **B3. Providing MD with Patient's Advance Directive**

- \* Any statement or question regarding whether or not the physician should be given a copy of the patient's living will. This may apply to a living will that already exists or a living will that the patient is considering writing in the future.
- \* If explicit mention is made of placing the living will in the medical record, J10 should be coded as well.

### **B4. Assistance in Obtaining Advance Directive Documents**

- \* *This code should only be used for physicians.*
- \* Use the proper code below to tag a speaker-turn where the speaker mentions how the patient might obtain a copy of an advance directive document.

#### **B4a. The physician can/will provide help with forms.**

- \* In speaker-turns where the MD refers to an actual document which is present in the room and which the MD plans to give to the pt, B4a should be coded. This might occur when the MD is pointing out something on a pamphlet about advance directives that contains forms. When the discussion turns to advance directives in general, and the

MD is not referring to a piece of paper present in the room, this code should not be used (but another B code should).

**B4b. Someone else can/will provide help with forms.**

- \* It must be explicit that the patient is being referred for the purpose of getting forms to complete to make an advance directive.
- \* Assistance in completing the form counts, if it seems like the person can provide a new form to complete.
- \* If the pt is to receive the form from a social worker or attorney, code the proper B5 code as well.

**B4c. Unclear who will provide help with forms.**

- \* This code is used when the MD talks about the patient getting forms, but it is not clear if the MD will provide the forms or if someone else will..

**B5. Referral to Social Workers or Attorneys**

- \* *This code should only be used for physicians.*
- \* Use the proper code below to indicate when the physician refers the patient to an attorney or social worker for **any** assistance with advance directives.
- \* Other forms of assistance (financial, estate will planning, organ donation, etc) should not be coded this way. In particular, if the MD sends the patient to a social worker for reasons unrelated to advance directives, it should not be coded.
- \* This is closely related to B4b, and often when B4b is used, a B5 code will be required as well. However, B5 does **not** require that the speaker state that the attorney or social worker will provide the pt with a form.

**B5a. Referral to an Attorney**

**B5b. Referral to a Social Worker**

**B6. True Description About Advance Directives**

- \* This codes should be used to tag a speaker-turn in which some true fact about living wills is queried or discussed.
- \* True statements about living wills in PA are
  - a. It does not need to be notarized.
  - b. You do not need a lawyer to prepare it.
  - c. It should be witnessed by two people.
  - d. Two MDs must conclude that you are terminal or in PVS for it to take effect.
- \* It is true that living will laws vary from state to state.
- \* In NC and at the VA, it is **false** that two MDs must conclude that you are terminal or in PVS.
- \* DPAs are usually notarized.
- \* Statement about what living wills are for (i.e. "to let us know what you want done should you become so sick that ..." which might be coded A4) are **not** coded B6.

**B7. Myths About Advance Directives**

- \* This code should be used to tag speaker-turns in which some false statement about the law regarding living wills or DPAs is made.
- \* False statements about living wills include:
  - a. You need a lawyer to prepare it.
  - b. In NC and at VA, two MDs must agree on terminal illness or PVS.

## C. DISCUSSION OF PREFERENCES: SCENARIOS AND TREATMENTS

- \* This category is intended to tag the different sorts of situations which are discussed in which a pt might have a preference.
- \* There are many ways that patients and their doctors work through feelings about treatment in certain scenarios. Any scenario or treatment which is brought up which in some way adds to the discussion about advance directives should be coded with a C code, even if the patient is never explicitly asked for a preference about it. This includes stories about friends and family members and public figures. *If the story has nothing to do with the advance directive discussion at all, it should not be coded, even if it refers to scenarios or treatments.*
- \* If the speaker is discussing what a living will might say, and uses these scenarios or treatments, they should be coded with one of these codes (along with the appropriate B code).

### C1. Dire Scenario

- \* This code is used to tag any turn in which the idea of a "dire" scenario has come up. "Dire" scenarios are situations, often vaguely defined, which are often characterized in the literature as "futile."
- \* The implication is that the situation is one in which the patient is vegetative, permanently unconscious, confined to an intensive care unit indefinitely, permanently on a respirator, imminently dying, etc..
- \* Terminal cancer is coded C1.
- \* Examples of "dire" scenarios are "terminal illness," "vegetative illness," "vegetable," situations in which there is "no hope," or "it's useless."
- \* C1 can be coded with C4 codes (probability codes) if the implication is that the probability is so low as to make the situation "futile," even though there is "a chance."
- \* Occasionally a patient may assume that the condition is curable, even though the MD has described a "dire scenario." In this case, C3 would be coded (along with C1 if the patient explicitly refers to the scenario as well).
- \* "Being kept alive" should be included here, unless the context makes it clear that the situation is not terminal or vegetative. If in the same turn there is a discussion about some disabling illness, and the "being kept alive" can be construed to refer to that illness, code C2 **not** C1.
- \* The following are situations which are **not** necessarily coded C1: sudden death (often coded C5, see below), cardiac arrest (often coded C5, see below), respiratory failure, etc. Similarly, just because one is "dying" does not mean the situation is "dire." (Generally, in scenarios, the patient is "dying," otherwise (s)he would not need medical treatment.) C1 implies that the patient will not get better no matter what is done.
- \* During the turn a C2 code is used, do **not** code C1 as well unless the speaker clearly and unambiguously is referring to a "dire scenario" **in addition** to the condition coded C2. (People may begin a description with dire words ("just to keep alive" but then later in the turn qualify the scenario to turn it into a C2). In some of these cases, and F1 or F2, and perhaps even an F3 code will be needed.
- \* If you cannot tell whether the code is C1 or C2, do not code it C1 or C2. Instead, merely use the proper F code.
- \* Often an F1 or F2 code will be needed in conjunction with C1.
- \* C1 can be coded in conjunction with codes C5-C8. Occasionally a patient may assume that the condition is curable, even though the MD has described a "dire scenario." In this case, C3 would be coded (along with C1 if the patient explicitly refers to the scenario as well).

## C2. Disabling illness.

- \* This code should be used to tag any turn about treatment a disabling illness, other than those which are "dire" and coded C1. In general, this will include any scenario which attempts to describe some "state-of-being" which this patient might be in, either before or after treatment. These states need to be somewhat chronic in nature.
- \* Acute emergencies (especially ones which are assumed to be reversible or probably reversible) generally are described by the **treatment** they require, rather than by a C2 code. (i.e. "If you got a bad pneumonia, would you want to be placed on a breathing machine?") They also **may require** the code C3 or a C4 code.
- \* C2 should **not** be used when a treatment is being discussed without any mention of a "state of being." (i.e. "Would you want to go on a respirator if your breathing suddenly stopped?")
- \* This should be used for statements like "unable to do the things you like to do," etc.
- \* If you cannot tell whether the patient is in a "dire" condition or "merely" disabled (perhaps severely), do not use C1 or C2. Use the appropriate F code.
- \* If it is apparent that the speaker is describing some state of disability which is not "dire," but there is not enough information to know what that state is like, use C2 along with an appropriate F code.

## C3. Reversible Illness/Cure Assumed.

- \* This code is used if no uncertainty about the outcome is acknowledged. Discussions about "a reversible condition, like pneumonia" would fall into this category. However, if a probabilistic expression is used ("pneumonia, which we usually can cure"), it should be coded C4x, below.
- \* If the patient is assuming that (s)he can be cured without acknowledging any probability of not being cured, code this.
- \* This might rarely be used in conjunction with C1, if the MD is describing a "dire" situation, and in the same turn, the patient makes a **direct reference** to the situation and also assumes cure. ("If I'm in a coma, I want you to do whatever you have to to cure me.")

## C4. Probability

### C4a. Quantitative Probability

- \* This code is used if some quantitative statement is made about the probability of recovery.
- \* Near 0% and near 100% are coded here.
- \* Zero percent chance of recovery is **not** coded here. It is only coded C1.
- \* One hundred percent chance of recovery is coded C3, **not** C4a.
- \* This code can be used in conjunction with C1 if the probability is very low and the implication is that most people would deem it "futile" to try to treat.

### C4b. Qualitative Probability

- \* This code is used if there is some qualitative statement made about the probability of recover.
- \* There needs to be some (qualitative) quantifier attached to the chance or hope. Statements about "a hope" or "a chance" are **not** coded C4b. They are coded C4c.
- \* Examples include "usually recover," "some hope," "a good chance," "reasonable hope."
- \* "Reasonable hope" is also coded F1c.
- \* Statements in this category should **not** automatically be coded as F1 or F2 "vague" terms, unless other elements in the scenario other than the probability are also vague. (Except "reasonable hope," which is always coded both C4b and F1c.)
- \* Only code statements referring to the probability of recovery. Rarely, the word *chance* may be used to refer to **opportunity**. This should not be coded C4b. (i.e.: "We would

wait long enough to give you an adequate chance of recovery." This is coded C4c (uncertainty is acknowledged), but not C4b (reasonable refers to opportunity and not amount of probability).

- \* This code can be used in conjunction with C1 if the probability is very low and the implication is that most people would deem it "futile" to try to treat.

#### **C4c. Uncertain Event, No Probability Described**

- \* This tag should be used when the notion that **any** uncertainty would affect the patient's wishes is discussed. (Usually, the implication is that the patient would want to be treated if there was **any** chance.)
- \* This tag should be used if uncertainty is acknowledged, but no statement of probability is made.
- \* Includes words like "if there was a hope," "any chance," etc.
- \* This code can be used in conjunction with C1 if the implication is that most people would deem it "futile" to try to treat.

#### **C5. CPR**

- \* Discussion involving CPR, which may be variously described as "CPR," "resuscitation," "pounding on your chest," "trying to get your heart started," "electric shocks" "paddles" etc.
- \* Scenarios of "sudden death" and "cardiac arrest" are included here. (Including: "if your heart and lungs suddenly stopped")

#### **C6. Mechanical Ventilation**

- \* Discussion about breathing machines, intubation, mechanical ventilation, respirators, etc.
- \* Do not code this if intubation is mentioned **solely** as part of a description of CPR.

#### **C7. Artificial Nutrition/Hydration**

- \* Tube feeding, IV fluids, etc for maintenance therapy.
- \* IV fluids for the purpose of acute resuscitation are **not** coded C7 (but rather C9).

#### **C8. Admission to ICU**

- \* Whether or not the patient would want to be admitted to the Intensive Care Unit.
- \* If the speaker is talking about "intensive care," but not specifically about the act of admission to an ICU, it is a "vague term" and should **not** be coded here.
- \* The rule of thumb is: if the words "Intensive Care Unit" are used (or admitted to "Intensive Care") code C8. If the words "intensive care" or "intensive care therapy" are used, code F2b.

#### **C9. Desire for Other Specific Therapeutic Intervention**

- \* Any other specific intervention mentioned.
- \* Do not code for specific drugs which have no relevance to the patient involved in the discussion. (i.e. "They started grandma on Inderal." -- does not get coded C9 )

## D. PREFERENCES

- \* These codes mark preferences stated for or against intervention. These preference codes tag statements that the speaker is making about his/her opinion about the situation.
- \* If a spouse states that the pt **does not** want treatment under certain circumstances or that the pt **should not** want treatment under certain circumstances, this should be coded.
- \* *Physician opinions about what the pt ought to do or what in general ought to be done should **not** be coded here.*
- \* There is no need to code the scenario being referred to unless it is specifically repeated by the speaker in the turn. (Reference may be made by repeating part of the scenario or by using a pronoun to refer to the scenario.)
- \* If the speaker merely says "yes" or "no" or some other similar short phrase, but it is in response to a question that makes it clear that a preference is being stated, use a D code. If the previous turn included more than one question, and it is not clear what the patient is responding to, do **not** use a D code.

Example:

MD: So you do not want treatment if there is no hope. But if there is a chance, you want it.

PT: Yeah.

- \* In the same turn, if the speaker indicates a preference for treatment in one situation, but declines treatment in another situation, both D1 and D2 should be coded.

### D1. Preference for Treatment.

- \* Any statement that a patient would want to be treated in a certain situation.

### D2. Preference against Treatment.

- \* Any statement that a patient would not want to be treated in a certain situation, or would not want to remain alive in a certain situation.
- \* Includes such statements, even if no specific treatment is mentioned. (i.e. "I would not want to live in a vegetative state.")
- \* Includes turns in which the speaker states that (s)he would be interested in euthanasia, suicide, Kevorkian, etc, if the statement was made in the context of what (s)he would want done in a certain situation. Do **not** code general statements about assisted suicide that are not directly tied to a scenario.

### D3. Declines to State Preference.

- \* Use this code **only for patients** (not for family members).
- \* This code will be used when pts have been asked to state treatment wishes, and decline to do so.
- \* Includes pts who are unsure, who feel that it should be left up to their family, or who just want the MD to decide.

### D4. Has Not Thought About It.

- \* This code should be used whenever the patient states that (s)he has not thought about the issue, whether it is regarding advance directives in general, proxies, specific treatment preferences, etc.
- \* D3 should **not** be used with this code (unless there is a separate statement in the turn which qualifies).

## E. PROVISION OF MEDICAL INFORMATION

- \* These codes tag communication regarding provision of information about facts **regarding medical treatments**. They can code inquiries for information, attempts by the physician to determine how much pt understands (Do you know what CPR is?), or the actual provision of medical information.
- \* The purpose here is to convey information about actual treatments, prognoses with certain treatments, etc.
- \* When a discussion intended to explicitly explain what is meant by "life-sustaining treatments" occurs, it should be coded with the appropriate E code and with F3.

### E1. Description of Medical Procedure

- \* This includes discussions that provide descriptive information about a medical procedure.
- \* "Descriptive information about a procedure" includes what it does, how it works, what it feels like to undergo it, what the possible outcomes are.
- \* Information about the pt's prognosis given a specific treatment should be coded here (e.g. With your lungs the way they are, if you were put on a ventilator, we'd have a hard time getting you off.)
- \* The description must provide real information to be coded here. For example: "CPR is when we try to restart the heart," and "A ventilator is a breathing machine." do **not** provide more information about the process and should **not** be coded here.
- \* Turns about "chest compressions" and "shocking the heart" sometimes are coded here and sometimes are not. If they are offered only as interventions, they should just be coded C5. If they are intended to explain what goes on when one gets CPR, they should also be coded E1.

### E2. Request for Information about Medical Procedure

- \* This code should **never** be used for physicians.
- \* Patient or family member requests information about a medical intervention.

### E3. Determines What Patient Knows

- \* *This code should **only** be used for physicians.*
- \* Physician attempts to determine what a patient knows about a specific medical intervention, either by asking directly ("Do you know what CPR is?") or indirectly ("What do you know about CPR?")

## F. VAGUE TERMS

- \* This category will be used to tag turns in which vague terms appear. It will also be used to tag turns where an attempt is made, either by a statement or an inquiry, to specify precisely what is meant by the term.
- \* F1 codes will be used to code a few frequently-used vague terms separately. However, whenever the situation is vague, if an F1 code is not appropriate, and F2 code should be used.
- \* This code (especially F2 codes) does not apply just to specifically identifiable words or phrases. If the speaker is trying to identify or describe a situation or intervention, but that situation or intervention is vague, use the appropriate F code.
- \* A rule of thumb is: if the speaker does not give enough information to be able reasonably to make a treatment decision or to be able to reasonably interpret a treatment decision, then you should use an F code. Furthermore, if the words can easily be misconstrued or interpreted many different ways, use an F code.

### F1. Vague Situations/Interventions of Particular Interest

- \* Use the proper code below to code the particular word or phrase if it comes up. Read the rule carefully to be sure that the turn fits the code. We are looking for specific words or phrases here, not concepts.

#### F1a. Heroics

- \* Use whenever "heroic means," "heroic measures," "heroic treatments" "heroics" is discussed.

#### F1b. Machines

- \* Do **not** code "breathing machines" with this code.

#### F1c. Reasonable Hope

- \* Use whenever "reasonable hope" or "reasonable chance" are discussed.
- \* *Also code C4b.*

#### F1d. Vegetable

- \* "Vegetable," "vegetate," "vegetative state."
- \* *This will also need to be coded C1.*

#### F1e. Terminally Ill

- \* "Terminal," "terminally ill," "terminal illness"
- \* *This will also need to be coded C1.*

#### F1f. Quality of Life

- \* Code the words "quality of life," not the concept.

#### F1g. Natural Death

- \* This code should be used if the speaker uses the words "natural death," or "die naturally." It is the **words** that should be coded, **not** the concept.

### F2. Other Vague Terms

- \* The proper code below should be used to code any vague term/concept which was **not** coded with an F1 code.
- \* Determining whether a statement is vague is done in context of the preceding conversation and the present turn. Do not refer to future turns. Ask yourself: "Do I understand what the speaker means?" If you are not sure what is meant, it is vague. Use the rules of thumb described above.
- \* F2a and F2b may be used together in the same turn, but they may only be used once each in the same turn.

#### F2a. Vague Scenarios/Outcomes

- \* This applies to any vaguely-worded state of being, illness, disability, etc.

- \* Do not use this code for vague probability statements (which are generally coded C4b).
- \* Examples: "brain dead" "if I'm not useful" "if I can't do anything" "incapacitated" "very sick"
- \* Vague scenarios may be directly related to vague treatments. For example "when you've already tried everything" refers to both a vague treatment (everything) and a vague scenario (the time at which everything has been tried).
- \* Sometimes specific health states can be vague. "Stroke" can be vague when it is a scenario for which the pt is asked to state a treatment preference, because we do not know how bad a stroke would make the preference operative. However, when stroke is being used strictly as a disease and not to describe a state-of-being ("I would not want to have a stroke." or "What causes a stroke?") it is **not** vague.
- \* Do not code incompetence or *decisional* incapacity with F2a, as long as this is what is clearly being referred to. If the word *incapacity* is used so that it clearly refers to decisional incapacity, do not code F2a.

#### **F2b. Vague Treatments**

- \* This applies to vaguely-worded treatments, "life-sustaining treatment," "life support," etc.
- \* As always, context is important. If it is clear what treatments are being referred to, do not code F2b. Just because specific treatments have been mentioned (even in the same turn) does not mean that these vague terms are not vague. If it is *clear* from the context what they are referring to (it helps to ask yourself: do I know if this refers to antibiotics? Does it refer to artificial nutrition and hydration?) do **not** use this code.

### **F3. Specification of Vague Terms**

- \* These codes will be used when the speaker is trying to clarify what a vague term means.
- \* If the vague term being clarified is first mentioned in the same turn as the clarification, the proper F1 code should be used as well.
- \* Examples of ways that terms might be specified:
  - a. Giving an example -- the speaker gives an example of the type of thing (s)he is talking about, e.g. "breathing machines, and things like that ..."
  - b. Asking directly -- "What do you mean by "machines?" "Is a 5% chance a 'reasonable chance'?"
  - c. Statements like: "There are lots of different types of life-sustaining treatments, like ..."

## G. REASONS/VALUES/GOALS

- \* Values describe what is important in life and what makes life worth living. (Self-sufficiency, being free from pain, having "quality" life, having friends)
- \* Goals describe the purpose of medical care. Usually goals promote values. (Keeping the pt comfortable, prolonging life as long as possible, promoting "quality" of life.)
- \* Reasons describe the rationale for certain treatment wishes, for beliefs about life-sustaining treatment, for prior decisions. These are not reasons for having a living will in general (although they may be reasons for having a particular set of treatment instructions in a living will, of course).
- \* Reasons should give us some information that goes beyond the actual state or scenario being discussed. A restatement of the scenario is NOT a reason.
- \* When people talk about things which are important to them to make life worth living: i.e. intellectual functioning, independence, etc -- these are coded with a G code. When people talk about disabilities for which they do not want treatment (dementia) which are codeable with a C code (and perhaps with an F code) these generally do not get G codes.

### G1. Eliciting Values and Goals and Reasons

- \* Use this code when speaker tries to elicit the pt's values, goals, or reasons.
- \* Anytime a physician mentions a possible reason which the patient may have or a reason which some patients have for a treatment decision, it should be coded G1, **unless the doctor implies that the reason is one which the patient ought to have** (i.e. that the doctor agrees with the reason). In this case, code G2.
- \* If speaker asks what an acceptable quality of life is -- this is coded as G1, along with F1 and F3.

Examples:

- Are you the kind of person who wants us to prolong your life no matter what, or do you want us to consider the "quality" of life?
- What was it about your mother's condition that made you feel that way?
- Why?
- Sometimes people have religious reasons to refuse treatment.

### G2. Statements of Values, Goals, and Reasons

- \* See G1 for definition of values, goals, and reasons.
- \* These are statements which the speaker believes to be valid values, goals, and reasons. If the patient states them, (s)he is talking about his/her beliefs. If the physician states them, (s)he implies that these are good reasons for the patient to act in a certain way.
- \* Words like "burden," "suffering," "pain," "dependent," "futile" should be coded as reasons (even if they are **also** scenarios).
- \* If the physician mentions reasons only to see if those are the patient's reasons, code as G1. Similarly, code G1 if the physician brings up reasons that some people might have, without implying that they **ought** to apply to the patient.
- \* If the physician merely repeats a reason mentioned by the patient, it does not need a G code. (It may need a communication code below.)

### G3. Reasons of Particular Interest

- \* There are several specific reasons of special interest, which will be tagged separately, with the codes below.
- \* These codes **may be used** for reasons for just having an advance directive.

#### G3a. Not wanting to be a burden on others.

- \* Includes the desire to eliminate the need for family members to "have to decide" unless guilt is specifically mentioned.

- \* If this is a reason for a particular treatment decision (I don't want to be treated as a vegetable), code G1 or G2 as well.
- \* If this is a reason just for having an advance directive, do **not** code G1 or G2.

**G3b. Not wanting others to feel guilty.**

- \* This may be coded even if it is given as a reason for having a living will or talking with the family.
- \* Only code as G1 or G2 if it is discussed as a reason for a treatment preference, etc.
- \* Do not code G3a with this.

## H. SURROGATES

### H1. Surrogate - NOS

- \* Any discussion which relates to surrogates, and cannot be coded below.
- \* This code should never be used in a turn which is also coded with an H2 code or H3.
- \* Includes attempts to identify a surrogate decision-maker, either by stating directly ("My son is going to make decisions for me."), asking directly ("Is there someone who should make decisions for you?"), or trying to identify the appropriate person ("Who is your next of kin? Have you discussed your wishes with anyone?")
- \* Includes statements by the patient which relate to whether or not (s)he has a surrogate, the suitability of certain individuals as surrogates, whether or not (s)he wants a surrogate, etc, unless the statement is also coded H2 or H3.

### H2. Identity of a Surrogate

- \* Use the proper code below in the turn in which the patient identifies a likely surrogate. Do not code if it becomes clear later that the person identified is **not** intended to be the surrogate.
- \* If someone else reports that the patient named a particular person on a duly-executed durable power of attorney, the corresponding H2 code should be used. However, if someone other than the patient reports that the patient **intended** to give someone this power, but did not, it should not be coded with an H2 code. (An H1 code would be appropriate unless H3 is applicable in the turn.)
- \* Use only the **first time** the surrogate is identified.

**H2a. Spouse**

**H2b. Child/children**

**H2c. Sibling**

**H2d. Other relative**

**H2e. Friend**

**H2f. Other**

### H3. Discussion with Surrogates

- \* Use this code when the doctor suggests that the pt have a discussion with a surrogate, potential surrogate, or likely surrogate about treatment preferences or having a living will.
- \* Use this code when the pt states that (s)/he has had a discussion with a surrogate, potential surrogate, or likely surrogate, or when (s)/he states that (s)he plans to or ought to have this discussion.
- \* Use this code if the physician asks the patient whether or not (s)he has discussed his/her wishes with anyone, **only if** anytime later the pt states that (s)/he has had a discussion with a (potential or likely) surrogate. (This will give "credit" for initiating the discussion to the MD.) This rule applies as well if the physician asks the pt if the (potential or likely) surrogate knows his/her wishes.
- \* If the patient states that surrogate "knows" his/her wishes, only use this code if it is clear that (s)he means that (s)he has had a conversation about wishes.

## J. COMMUNICATION

### J1. Future Conversations

- \* Any discussion which implies that there is the opportunity to discuss this again in the future between the physician and patient.
- \* Includes comments that the pt does not have to make up his/her mind at this visit and offers to discuss again at a specified or unspecified future visit.

### J2. Current Health is Not Reason for this Discussion

- \* Reassurance that this discussion is not related to physician fears that the end is near.
- \* This code may be used even if current health is the reason for the discussion, if the MD makes a reassuring statement implying that (s)he is not having this conversation because the pt is going to die soon.

Example:

"It's worthwhile having this discussion now because you have heart disease, but that doesn't mean that I think you are going to die soon. It's just good to be prepared."

*This would be coded both J2 and A6.*

### J3. Can Change Mind

- \* Reminder to pt that (s)he can change his/her mind.
- \* Any discussion of the mechanics of changing an advance directive ("just rip it up and let everyone who had a copy know.")

### J4. Positive Feedback to Patient

- \* Statements like "It's good that you wrote a living will," "This conversation helps me," etc.
- \* It needs to relate to some behavior exhibited by the patient, and to be relevant to the discussion about advance directives.

### J5. Reflection

- \* This is only coded for the physician.
- \* This is coded when the physician checks his/her own understanding of what the other speaker said by repeating it or interpreting it. It **must** be clear that the patient may have meant what the physician is proposing.
- \* Includes verbatim repetition, or paraphrasing of what the previous speaker said within the **last three speaker-turns**. Repetition or paraphrasing of information not referred to by the patient within three speaker-turns (which usually contains two patient turns) should not be coded J5.
- \* May include attempts to draw out the meaning of short phrases.

Example:

MD: Would you want treatment if you were in PVS?

Pt: No

MD: So you would not want treatment if you were in PVS, right?

(This is coded J5, along with others, including C1, F1d)

- \* It does **not** include statements which have no basis in what the previous speaker said. Statements like this are more likely to be "leading statements."

### J6. Emotional Response

- \* Any statement about the emotional response to **having this conversation**.
- \* Pt statement that this is hard to talk about qualifies.
- \* MD asking if this is difficult to talk about.
- \* Sometimes statements that "it is hard to talk about" refer to a cognitive difficulty rather than an emotional one. If this is clearly the case, do not code J6.

Example: "It's hard to think about a situation you've never been in."

**J7. Physician Opinion About Preferences**

- \* Any opinion expressed by the physician regarding appropriate treatment.
- \* Only code for the physician.
- \* Includes statements agreeing or disagreeing with patient preferences, statements about what MD wants for self, statements about what MD has done or would do with family, etc.
- \* This does not apply to statements about having advance directives, only about specific treatment preferences.

**J8. MD Leading Statements**

- \* Physician statements and questions which lead the patient to state a preference (for treatment or for a particular proxy) which (s)he has not already stated or implied and statements which assume that the pt has a preference which (s)he has not already stated or implied.
- \* Be sure that the patient has not implied the statement in previous discussion. ( A summary statement by the MD of the discussion can look the a leading statement but it is not, even if it is phrased in a "leading" way.)
- \* Needs to be relevant to the advance directive discussion.

**J9. Missed Opportunities**

- \* This is a purely subjective code which coders should use if they feel that the situation "cried out" for the MD to say or do something, and the opportunity was missed.
- \* We are not checking reliability on this code. It is just a way to tag text that someone thinks is interesting in this particular way so that we can go back and look at it.

**J10. Documenting in the Medical Record**

- \* Code if speaker refers to documenting the discussion in the medical record.
- \* Code if speaker refers to placing a copy of an advance directive in the medical record. It is **not** enough for the patient just to be bringing it in for the doctor to see.
- \* This applies to discussion that the advance directive should **not** be placed in the record and to statements that the advance directive is not currently in the record.

## **K. FRIENDS AND FAMILY**

### **K1. About Patient's Family or Friends**

- \* Any discussion about an illness scenario involving the pt's friends and family.
- \* Any discussion about friends and family having (or not having) advance directives. Also includes stories about having had to make decisions for others.
- \* The scenario needs to be related to the discussion of advance directives in some way. (If it is a complete digression that is not at all relevant to the discussion, do not code it at all, even if it refers to ICUs, ventilators, etc.)

### **K2. About MD's Family or Friends**

- \* Any discussion about an illness scenario involving MD's family or friends.
- \* Any discussion about having advance directives involving MD, his friends, or family.
- \* It must have really happened and not be hypothetical. (Statements about what an MD **would do** with a relative might be coded J7).

## **L. FAMOUS PEOPLE**

### **L1. Famous People with Living Wills**